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ABSTRACT

This monograph reports on an October 1991 forum on self-advocacy for persons with mental retardation in the leadership of The Arc, a national organization on mental retardation. The monograph is intended to help local chapters encourage the empowerment and inclusion of individuals with mental retardation as both members and leaders. First, principles of the Americans with Disabilities Act are identified and applied to community organizations, especial Arc chapters. The forum involved 13 representatives of self-advocacy groups, parents, professionals, and Arc leaders and addressed the following concerns: reasons for people with mental retardation to become Arc leaders; leadership abilities of people with mental retardation; beliefs and structures which prevent such people from becoming leaders in The Arc; and the role of Arc chapters in supporting and promoting leadership. An appendix lists forum participants. (DB)

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A CALL TO ACTION!

The Roles of People with Mental Retardation in Leadership

EC 301884

The Arc

a national organization on mental retardation

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A CALL TO ACTION!

The Roles of People With Mental Retardation in Leadership

The Results of The Arc's Forum on Leadership
Portland, Oregon
October 23 - 24, 1991

The Arc
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The Arc

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FOREWORD

The Arc, as the nation's largest volunteer organization concerned with all people with mental retardation and their families has, for over forty years, strived to enable people with mental retardation to be actively involved in all aspects of community life. Consequently, we recognize that the organization itself - The Arc - must exemplify this mission, and demonstrate our own commitment to achieve this valued societal goal.

In pursuit of this goal, The Arc's 1991 national board of directors called for "a national forum regarding self-advocacy" and to "develop strategies and materials to assist self-advocates in achieving all levels of leadership in The Arc." The charge for meeting these objectives went to The Arc's national Self-Advocacy Committee, which is composed of people with and without disabilities. Under the committee's leadership the forum was successfully convened during The Arc's 1991 national convention in Portland, Oregon. This resulting report summarizes the discussions which centered on how people with mental retardation could increase their involvement as leaders in The Arc.

It is imperative that our nation recognize the intrinsic value of people with mental retardation, who have an equal and important place in the community. But before we can expect society to embrace this principle, we throughout The Arc must exemplify this belief. So, with great pleasure we present this report, and with much encouragement urge all chapters of The Arc to undertake the empowerment and inclusion of individuals with mental retardation as both members and leaders within our and other organizations.

James B. Gardner, President
The Arc

A CHALLENGE FOR CHANGE

The Americans with Disabilities Act (ADA) is redefining how our nation views and treats people with disabilities. It is a law meant to open doors for people with disabilities and provide them increased opportunities across the spectrum of everyday life - from employment and use of public transportation, to adaptations in telecommunications and access to public accommodations. The ADA requires the integration of people with disabilities into the mainstream of their community and reconsideration of the roles these individuals hold within our society.

The ADA challenges businesses and communities to accommodate people with disabilities. Likewise, The Arc faces these challenges. As an advocate for the rights of people with mental retardation, The Arc should exemplify the spirit of the ADA: that doors of opportunity can be opened for people with mental retardation and other disabilities. It is in this vein that The Arc, and the community as a whole, is challenged to actively include and accommodate individuals with mental retardation and related disabilities.

SELF-ADVOCACY AND LEADERSHIP

Paramount to the success of a disability-focused organization's growth and goal achievement is that of having a membership that produces leaders: people who are willing to be active volunteers, creative committee members, committed board representatives and contributors in other crucial roles. The strength and future of organizations such as The Arc lies with people of this caliber.

In the recent past, people with mental retardation have increasingly demonstrated their desire to be leaders and actively participate in those areas which most affect their lives. Involvement of people with mental retardation may be most evident by the increase in the number of self-advocacy groups across the country from 55 groups in 1980 to more than 500 in 1992.

The growth of this movement, along with the noted benefits in the lives of people with mental retardation is well documented and increasingly recognized for its

importance (Browning, Thorin & Rhoades, 1984; Rhoades, Browning & Thorin, 1986; Eddy & Cohen, 1989; Wehmeyer & Berkobien, 1991). Self-advocacy groups, composed of individuals with mental retardation and related disabilities, meet regularly to collectively advocate for their rights, share information, provide mutual support, learn and socialize. Many groups elect officers, and some become incorporated entities. But most importantly, individuals with mental retardation involved in self-advocacy have demonstrated - when given opportunities, information and support - that they can be self-determining, assertive, creative and empowered to control their own lives. They have demonstrated the abilities to be leaders when the opportunities exist for them to demonstrate these abilities.

The Arc should exemplify the spirit of the ADA

LEADERSHIP AND CHAPTERS OF THE ARC

Individuals with mental retardation should be included and involved in all aspects of the community, not just as members and leaders of The Arc and other disability-related organizations. They should serve on community boards, municipal planning committees, state councils, federal advisory panels and in other decision-making positions. The Arc, however, should be at the forefront of providing individuals with mental retardation leadership opportunities.

Chapters of The Arc vary in how and to what degree people with mental retardation participate in leadership roles. Many chapters provide leadership opportunities for people with mental retardation and support these members in becoming more effective leaders. Others are just now starting to involve people with mental retardation in chapter leadership activities.

Many chapters, wanting to avoid "token" gestures of involvement, admit they lack the knowledge and information necessary to help the individual be a truly effective leader. These chapters, as well as other organizations, are seeking guidance on how to include individuals with mental retardation in the organization's leadership or improve upon how individuals currently in these positions can become better leaders.

There is relatively little information available in the area of building leadership skills in people with mental retardation. A paucity of information and the increasing desire of chapters to involve people with mental retardation in leadership roles became the primary catalyst to convening a forum to discuss leadership of people with mental retardation within chapters of The Arc as a step to broader, more inclusive leadership in the community.

THE FORUM PROCESS

The forum was scheduled for the 1991 national convention of The Arc in Portland, Oregon to allow those attending the convention the opportunity to also participate in the forum. Additionally, Oregon, as the birthplace of the People First movement in the United States, seemed appropriate since the forum was an activity driven in part by the self-advocacy movement.

The forum was a one-day, semi-open meeting. Thirteen "core group" participants representing self-advocacy, parents, professionals and leaders of The Arc were invited to the meeting (see Appendix A).

The forum was open for audience observation and, at designated times, audience comments. Those who observed the forum were also given the opportunity to contribute their thoughts and comments.

During the forum, core group participants broke into two smaller working groups to discuss the issues with a facilitator for each group. The audience comprised a third group and was also assisted by a facilitator. Small working groups and the

audience were then asked to discuss the following questions:

Why should a person with mental retardation be or try to be a leader in The Arc? Can a person with mental retardation be a leader in The Arc? Why or why not?

Would or does a person with mental retardation make a different type of leader than a parent or professional staff person? Why?

What are barriers in an organization such as The Arc that might prevent a person with mental retardation from becoming a leader?

Some people with mental retardation are assisted in leadership roles. Is this form of leadership effective? Why or why not?

What are chapters of The Arc doing in terms of supported leadership? Are there some good strategies or ways that work in helping people with mental retardation become effective leaders?

What <u>should</u> The Arc be doing in regard to people with mental retardation and leadership?

THE RESULTS

After both small and large group discussions, the notes, comments and recommendations of the facilitators were synthesized to reflect the general outcome of the forum. Many of the comments were pertinent to several of the questions asked at the forum, so comments and recommendations were organized under the four categories of questions noted below. The facilitators also expanded upon some points to assist readers in gaining a more complete understanding of the discussion surrounding the comments and recommendations.

Why should people with mental retardation be leaders in The Arc?

- People with mental retardation as leaders bring with them a passion and a vision brought about by dependence and discrimination that cannot be duplicated by those without disabilities. They are the real experts in mental retardation!

- The presence of people with disabilities in leadership roles, such as on boards and committees, provides a *reality check* for

the board and places a face with the mission, minimizing the risk of becoming too distant from the true purpose of the organization.

- People receiving services and supports are more likely to use and benefit from such activities if they have a sense of ownership and a commitment to the goals of the organization.

- People with mental retardation in leadership roles can both assist and serve as role models for other people with disabilities "coming up through the ranks."

- People with mental retardation in leadership roles are examples for people without disabilities, and provide expectations of outcomes beyond stereotypes and stigma.

- People with mental retardation in leadership roles serve as teachers to their peers striving toward self-determination.

- The presence of people with mental retardation in positions of leadership is recognition of the inherent rights of human beings to become self-determining and to participate in decisions affecting their lives.

- Because people with mental retardation often want and have something to contribute, there is a desire to contribute to the chapter and community.

- People with mental retardation constitute a potential substantial volunteer base at a time when volunteerism is on the decline.

- Adaptations and accommodations which enable people with mental retardation to become effective leaders may also benefit other people in leadership roles, independent of the presence or absence of a disabling condition (e.g., people with the limited ability to read English).

...people with mental retardation can become effective leaders.

- A chapter of The Arc can be a supportive environment in which to gain leadership experience. People with mental retardation often do not have exposure to life experiences that

help them develop the skills associated with leadership (i.e., self-determination, assertiveness, decision-making). Skills, opportunities and experience can be learned and improved by working with The Arc, then transferred to other areas of community responsibility (e.g., member of the city's parks and recreation committee, Mayor's committee on disability).

- In the ongoing effort to advocate for and stand in solidarity with individuals with mental retardation and their families, The Arc must take the lead and set an example for other organizations.

Can people with mental retardation be leaders of The Arc?

- Yes. People with mental retardation offer vision and a voice, engendered by the experience of living with the condition, which is an important perspective. People with mental retardation also have individual talents, experiences and viewpoints which can be beneficial to the existing leadership.
- Yes. The rapid growth of the national self-advocacy movement demonstrates that, with adequate *support* and *opportunity*, people with mental retardation can become effective leaders.
- Yes. Leadership includes elected and appointed participation at all levels, including state and local committees, volunteers, boards of directors as well as national level activities. There should be a leadership role for anyone willing to commit the time and effort.
- Yes. Because individuals with mental retardation are representative of The Arc and community-at-large.

What prevents people with mental retardation from becoming leaders in The Arc?

- An inaccurate, self-fulfilling prophecy, held both by some people with mental retardation and those who do not have a disability, that people with mental retardation cannot be leaders.
- The formal structure of governance, including parliamentary procedure, may make some

other leadership activities difficult for people with mental retardation who have difficulty understanding complex processes. Methods or routines used to conduct some leadership responsibilities may not be "cognitively accessible" to these individuals.

...take time to explain issues, situations and events.

- The lack of functional education and training which can help increase the skills and knowledge necessary to effectively participate.

- The lack of accommodations provided to people with mental retardation to enable them to fully participate in the leadership process. These may include adaptations of materials, accessible transportation and/or the availability of someone to take time to explain issues, situations and events when a person with mental retardation indicates he or she does not understand.

- A lack of lifelong opportunities for self-determination, control and participation over one's life. People with mental retardation can feel inadequate or embarrassed when they have not had lifelong experiences with success and control which would provide them with the self-confidence to assume leadership roles.

- A double standard as to the expectations for people with mental retardation in leadership positions. Inadequacy and incompetence are frequently tolerated for leaders who do not have a disability because of political or other reasons, yet people with mental retardation are often excluded for shortcomings which may stem from inadequacies in the system.

- The belief that if people with mental retardation are included, it will always slow or modify the way in which the committee, board or other activity functions, and thus make more demands on board members' time.

- Conflicts in interests between professionals, parents and people with mental retardation. It is often easier to proceed without having to deal with these issues.

- Historical reasons. The Arc is a parents' organization, started by and controlled by parents. Some parents may be less willing to allow their child to be independent and share in chapter policy-making.

Foster the development of leadership and self-determination.

- Leadership often requires verbal communication which is often not a strength for people with mental retardation. To further complicate matters, the language of The Arc is often filled with jargon, acronyms and technical phrases.

- People without disabilities do not know what it is like to have a disability and sometimes lack the empathy and understanding to encourage and support a person with mental retardation in a leadership role.

What can chapters of The Arc do to support and promote leadership?

- Make it a priority to provide adequate representation of people with mental retardation at all levels of leadership. Physical presence alone does not ensure effective participation, but absence from these roles guarantees that people with mental retardation will not learn to be leaders!

- Make members and other volunteer leaders aware of the importance of including people with mental retardation in leadership positions. Other people become sensitive to these issues through awareness and visibility.

- Provide instruction in parliamentary procedures and other formal structures of leadership.

- Provide experiences conducive to success. Leadership begins with committee experiences, and only after time does it progress to roles such as board membership or other elected office. Placing people in leadership roles for which they are unprepared may result in failure.

- Foster the development of leadership and skills of self-determination by encouraging/supporting groups (i.e., self-advocacy groups) and enabling

people to experience control. Education is important, but too often professionals' and parents' solutions to the problem are to relegate the person with a disability to the student role. It is as important to promote self-determination as it is to teach it.

- Ensure that volunteers, and not the staff, provide necessary supports to other volunteers who have mental retardation.

- Provide leadership training as sessions at conferences of The Arc.

- Encourage people with mental retardation to become members of The Arc and take active part in all activities.

- Provide opportunities for people with mental retardation to participate in a wide-range of leadership activities (e.g., attend conventions, seminars).

- Provide "supported leadership" (i.e., necessary adaptations and supports which enable the person with mental retardation to effectively participate in leadership activities). Supported leadership should be as variable as the individual characteristics of each human being, but some examples include:

  - Pair board or committee members with and without disabilities so that the person with mental retardation has access to a "partner" if necessary. Make sure that the individual with mental retardation knows how to contact that person. In fact, mentor programs for all new board members are probably a good idea!

  - Allow people with mental retardation to pick a support person to assist them. The individual with mental retardation should be given the opportunity to choose the level of help or support he or she needs. It should not be assumed the person needs or requires a certain degree of assistance.

  - Prior to board or committee meetings, provide tutorials or have a pre-meeting on issues to be discussed during the meeting and procedures to be used to conduct the meeting.

- Provide materials or use methods which are "cognitively accessible" (e.g., minimize the use of written materials, present written materials orally during the meeting or beforehand, provide tape recorded copies of written materials, picture-code the agenda).

- Distribute materials early. A person with mental retardation who cannot read may require extra time to review the materials with a support person.

- Set up co-leadership positions where two people (with or without disabilities) assume the responsibilities normally contained in a single position.

- Tape the board or committee meeting so that the person can replay the meeting to refresh his or her memory or to listen to discussion which he or she did not completely understand.

- Assign committee and board responsibilities according to individual skills, not simply on a random basis. Identify skills or strengths a person with mental retardation possesses or what he or she can contribute, then try to match the person with an activity.

- Finally, commit to working diligently to empower people with mental retardation to assume roles of leadership even in the face of doubt, discomfort or negative predictions.

SUMMARY

Can people with mental retardation be leaders of The Arc? Forum participants answered with a resounding yes! People with mental retardation bring unique abilities and life experiences which make them uniquely suited to serve in leadership roles. As one participant speculated, "What if one day the national president of The Arc was a person with mental retardation." What if?

There is much to be accomplished. Leadership does not happen overnight. The Arc must continue to be sensitive to the barriers that prevent people with mental retardation from participating in the process and must provide the support and affirmation necessary for people to succeed as leaders. The Arc should set an example by sharing leadership and by providing "supported leadership" to individuals with mental retardation.

For many of the participants in the leadership forum, this was the first opportunity to listen to people with disabilities and to consider a new role for them.... as leaders in The Arc. Forum participants voiced that this forced them to rethink their policies and practices. The leadership forum is a beginning step in a process of organizational inclusion. It is now in the hands of chapters and members of The Arc to take these recommendations and implement them. ❑

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Appendix A
Forum Participants

Brenda Doss, Alabama - (Forum facilitator). Parent of a daughter with mental retardation, board member of The Arc, chair of The Arc's Program Services for Children and Adults Committee, board member of ARC/Alabama.

Bruce Eddy, Missouri - Researcher from University of Missouri-Kansas City, author of publications on people with mental retardation and leadership.

Bob Furman, Washington - Former executive director of People First of Washington.

Chris Grandy, Pennsylvania - Self-advocate, active in self-advocacy movement in Pennsylvania.

Richard Robleto, Delaware - Member of The Arc's board of directors, advisor to People First of Delaware, chair of The Arc's Insurance Committee, past president of the Association for the Rights of Citizens with Mental Retardation in Delaware, parent of a daughter with mental retardation.

Valarie Schaaf, Oregon - Self-advocate, board member of The Arc of Oregon, active in People First of Oregon.

Clair Silver, Oregon - Board member of The Arc of Oregon, past board member of The Arc, board member of The Arc of Oregon's Guardianship, Advocacy & Protection Services.

Bertha Spinning, Oregon - Self-advocate, active in People First of Oregon, board member of The Arc of Oregon.

Mary Jane Starlings, Alaska - Executive director of ARC/Alaska, active in the National Council of Executives of ARCs.

Joan Thompson, Ohio - Board member of The Arc, member of The Arc's Program Services for Children and Adults Committee, past president of The Arc of Ohio, parent of a son with mental retardation.

Nancy Ward, Nebraska - Staff person for People First of Nebraska, chair of Steering Committee to Form a National Self-Advocacy Organization, chair of The Arc's Self-Advocacy Committee, board member of The Arc.

Rick Berkobien, Texas - (Forum facilitator). Assistant director of The Arc's Department of Research and Program Services, staff liaison with The Arc's Self-Advocacy Committee.

Dr. Michael Wehmeyer, Texas - (Forum facilitator). Project Director of The Arc's Self-Determination Curriculum Project, Department of Research and Program Services.

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